SUMMARY OF MAJOR FINDINGS AND RECOMMENDATIONS

Prepared by
The Human Services Research Institute

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BACKGROUND

The Human Services Research Institute (HSRI) has been charged to identify barriers in North Carolina to the implementation of self-directed supports and proposing steps to eliminate such barriers. This initial analysis focuses exclusively on a range of potential statutory constraints that currently or may in the future constrain the development of self-directed services for elders, people with physical disabilities, people with developmental and other cognitive disabilities, individuals with mental illnesses and people who experience substance abuse issues. HSRI is submitting this full report* concerning statutory constraints and recommendations whereupon attention will turn to identifying the potential constraints that rules, regulations and policies may pose.

WHAT IS SELF-DIRECTION?

Self-direction is a simple but powerful concept that promises to make traditional supports to people with disabilities, chronic conditions, and elders more flexible, more individually tailored, and ultimately more responsive. It is based on the assumption that because an individual requires support does not mean that he or she has ceded control over basic decisions regarding the time, place, nature, provider and duration of those supports. Self-direction assumes a "retail" approach to the provision of services (e.g., one individual at a time) compared to a "wholesale" (e.g., one size fits all) approach.

The specific application of self-direction will be different depending on the nature of the individual requiring support. One of the first applications of self-direction grew out of a movement in the physical disability community to control the hiring, firing and training of personal care attendants. The call for more control over personal care coincided with the larger independent living movement and rejection of more institutional models of care that circumscribed choice and inclusion.

With respect to behavioral health, the evidence of self-direction can be seen in the growth of consumer operated drop in centers during the 70s and 80s and, more recently in the expansion of peer support models and the use of advance directives that spell out the individual's wishes and preferences in

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times of crisis. In the case of individuals with substance abuse problems, self-direction might take the form of vouchers that can be used to purchase services from a range of vendors.

In developmental disabilities, self-direction has come to mean the participation of the individual in his or her person centered plan, respect for the individual's wishes and goals, the creation of an individual budget allocation, and varying degrees of control by the individual and/or family over the disbursal of such funds either directly or indirectly. Self-direction in developmental disabilities also entails the ability of the individual to make choices about where to live, what to do during the day and the staff that will provide support.

Among elders, the move to self-direction has also coincided with a move over the past several years to maintain individuals who are aging in their own homes as an alternative to placement in residential or nursing care facilities. Since each individual's situation (including natural supports from family and friends) is influenced by a variety of idiosyncratic factors including the degree of dependence, culture, routines and living situation, home supports likewise need to be geared to the specific needs and strengths of the older individual and his or her support network. The HHS/Robert Wood Johnson Cash and Counseling demonstrations illustrated the positive results when elders and their families were given the ability to control resources and direct funds to supports of their choosing, provided at their convenience.

The operational components of self-direction will also vary in their intensity and applicability depending on the group of individuals served. For instance, many people with physical disabilities do not need a "plan" to govern their services beyond the identification of need and resources. Other individuals may have very little interest in actually managing the day-to-day allocation of resources but instead will be content to chose and train their service provider. Given these assumptions, the following is a list of potential components that may, in varying degrees, be necessary to ensure the viability of self-direction.

- **Individualized plan** -- Because self-direction is inherently a highly individualized approach that revolves around the expressed needs and preferences of each person, it is critical that the process of developing individual supports starts with a formal or informal focus on the participant. While not every individual may need or want a plan if not required by a funding agency, when a formal process is indicated, the individual should be the focal point, and the active participation of individuals who are close to the person (e.g., family, friends, and other allies) should be solicited. The planning process should focus on the person's expressed preferences on how his/her needs would best be met.
- **Consumer control** -- Central to self-direction is the authority of the individual to select workers who provide supports, supervise them and, when necessary, terminate their services. It also includes the participant's ability to make choices among agencies that provide formal supports.
- **Participant allocation** -- Since each individual has different needs and may make different choices about the array of supports that will meet his or her objectives, it is vital that individuals have an identified budget with which to plan and direct toward specific supports.
- **Supports for self-direction** -- To assist and support the individual to make choices, identify relevant specialized and generic resources and manage services, the system should provide information and direction. Accumulated experience with self-direction around the country points to the importance of providing access to a personal agent,

broker, or other individual who can perform this role to the extent desired by the individual.

- **Financial management services** -- The presence of financial management services to carry out "back room" functions such as handling payroll taxes, workers' compensation, social security, and tracking the individual allocations can also enhance the ability of individuals to self-direct. Financial management services can support individuals to be the employers of their support workers and, hence, exercise direct control over hiring, supervising and firing workers.
- **Participant protections** -- Self-direction also poses new challenges to public monitoring systems. Since many self-directed supports will be provided in the individual's home or workplace – and not in a more formal setting – the traditional means of assuring the well-being of more vulnerable individuals may not be operative. As a result, it is important that public entities develop alternative monitoring strategies and other health and safety safeguards that are specifically tailored to individuals who direct their own services (e.g., easy access to criminal background checks). It is vital that these protections be respectful of individual choices.
- **Quality management** -- In order to manage self-directed services and supports at the sub-state as well as the state level, it is important to develop solid strategies to track the achievement of participant goals and personal outcomes.

PRINCIPLES

In order to guide this inquiry, it is important to spell out expectations and aspirations regarding self-direction against which to examine the current statutory and regulatory framework. This task is aided by the Statement of Principles developed by the North Carolina Consumer Directed Task Force and subsequently revised by the Consumer Directed Work Group and adopted by the North Carolina Long Term Care Cabinet. These principles have been updated for this analysis to also encompass elders and their caregivers.

People with Disabilities and Long Term Illnesses and Elders:

- Have the same needs, hopes, desires and feelings common to all people.
- Are entitled to the full benefits of community membership and citizenship, including all of its rights, privileges, opportunities, and responsibilities.
- Must be afforded the dignity of taking risks.
- Must have access to coordinated services and supports, determined by the individual's unique strengths, needs, and choices.
- Must have the opportunity to direct the planning, selection, implementation, and evaluation for their services and supports.
- Are the primary decision-makers in their lives and must be supported and encouraged to achieve their full potential and be afforded the opportunity to develop personal relationships, learn, work and produce income, worship and be full participants in community life.

Community Service and Support Systems Must Strive To:

- Provide safeguards to ensure personal security and wellbeing and affirm and protect individual legal and human rights.

- Be coordinated and person- and family-centered; developed around the individual's needs and strengths, capabilities, and choices.
- Be fully accessible, culturally responsive and provided in the most integrated community setting appropriate to the individual's needs and desires.
- Support the development of informal and generic community resources that are accessible and readily available, and employ specialized services only when those used by the general public cannot reasonably accommodate the needs of the individual/family.
- Be directed toward the enhancement of quality of life and the achievement of interdependence/independence, contribution, and meaningful participation into the community.
- Support people to be, to the extent possible, the primary decision-makers in their lives by providing them and their families/caregivers with the information and supports necessary to make informed decisions.
- Reflect best practice, be cost-effective, efficient, and achieve outcomes valued by people with disabilities and long term illnesses, elders and their caregivers.
- Be responsible stewards of public dollars, distributing resources to assure that individuals are served equitably and according to need and comply with all accountability requirements governing public funds administered by the system.
- Ensure that consumers or their designated representative meet the responsibilities they agree to assume with regard to directing their own care including making informed and cost-effective decisions regarding services and supports.

In sum, the Consumer Directed Task Force has very clearly identified the hallmarks of self-direction – most importantly that individuals have the opportunity to direct the planning, selection, implementation, management and evaluation for their services and supports; and that the service system ensures that supports are responsive, reliable, safe, and accountable. It was against this backdrop that the following analysis was prepared. The Major Findings section lays out key findings regarding those statutory provisions that may not be consistent with the foregoing principles. The Recommendations section offers recommendations for change.

MAJOR FINDINGS

General Statutory Issues Relevant to all DHHS Divisions

- To date the experience with self-direction has been limited in North Carolina across all of the populations covered by this project. As a consequence, there is a limited understanding of the tenets of self-direction, little in the way of positive examples in practice, and a minimal demand for the availability of self-directed supports;
- While there are no obvious restrictions on self-directed services in the pertinent NC statutes, there are also no provisions that directly address self-direction, define the outlines of self-direction, or affirmatively encourage its application;
- With respect to the Medicaid provisions in the General Statutes, there is no language that would stymie the implementation of self-direction, nor is there any affirmative authorization to seek federal reimbursement for self-directed services;
- The state has a foundation for consumer directed supports as it has been providing services through this mechanism through the Independent Living Program from Vocational Rehabilitation for many years. The state has taken some additional recent important steps toward self-direction through the design of the CAP/DA-Choices waiver and the Piedmont

Innovations waiver – both of which, when implemented next year, will provide important operational experience that may serve as a platform for expanded initiatives. It also is encouraging that the Department intends to apply for a Medicaid Independence Plus waiver that will operate side-by-side with the current CAP/MR-DD waiver program;

- Because self-direction anticipates that individuals will in most instances function as the legal employers of their support workers, the state will need to re-examine its workers' compensation laws. Positioning individuals as employers of their workers poses liability issues which can be mitigated if workers' compensation coverage can be obtained. North Carolina's present statute (Workers' Compensation Act contained in Chapter §97) does not appear to be especially well-geared to support self-direction. This topic bears further investigation;

- The lack of affordable housing is an obstacle to home and community services and, thereby, consumer-directed services. Except for the Special Assistance In-Home fund (which is limited to 800 slots), North Carolina does not furnish additional assistance to individuals who want to reside in their own homes and receive services. In contrast, individuals served in adult care homes and mental health group homes are eligible to receive State-County Special Assistance. State-County Special Assistance funding is not portable or designed to follow individuals into their preferred living arrangement.

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- According to the Final Report by The North Carolina Study Commission on Aging, the laws governing guardianship in the State have not been substantively changed since 1977. Since that time there have been numerous changes in the fundamental conceptions of guardianship including reforms that preserve the legal rights, freedom and autonomy of individuals. Although North Carolina law previously allowed limited guardianship the law was not clear. With the enactment of House Bill 1123 during the 2003 session of the General Assembly, the law was changed to expressly authorize the option of limited guardianship to all and to encourage consideration of its use. Rights reserved under limited guardianship align with the tenet of self-direction to make one's decisions to the extent possible, and provide for retaining the right to marry, to vote, to be a witness, to make a will, the privilege to drive, and the right to contract. Now that reform has been adopted, the state should initiate strong support in this needed reform area that crosses all populations encompassed in this study.

- While the provisions of a state's nurse practice act sometimes pose obstacles to self-direction, there are no provisions in North Carolina's law that raise red flags. §90-171 et seq. (Nurse Practice Act) governs the practice of nursing in North Carolina. §90-171.43 provides for nurse delegation of the performance of activities, and includes provision for delegating care (including to a member of a person's family) under the supervision of a nurse for services which are routine, repetitive, and limited in scope not requiring professional judgment of either a RN or LPN. As supervision is not defined, it may accommodate a variety of oversight methods such as telephone consultation, annual service plan development and review, in person instruction, and caregiver demonstration of competencies. Nurse delegation will be explored further during the next phase of project review.

- There do not appear to be provisions in statute for conducting criminal history checks of direct care workers who are hired individually by a consumer. In contrast, mandatory criminal history record checks are required in statutes §122C-80 for persons offered employment by an area program or by a contract agency of an area program, §131E-265 for employees of nursing homes and home care agencies, and §131D-40 for employees of adult care homes. It is unclear whether §122C-80 applies in the case of individual workers who are directly hired by

a participant. In the context of self-direction, persons who hire their own workers should be able to obtain criminal history checks. In addition, performing such checks is a critical safeguard.

Statutory Issues Relevant to Division of Medical Assistance

- Chapter §108A:54-70.5 (Social Services) authorizes the Department of Health and Human Services (DHHS) to establish and operate the state's Medical Assistance (Medicaid) Program. Going forward, the Medicaid program will play an important role in expanding opportunities for individuals to self-direct because Medicaid is the most important purchaser of long-term services and supports for elders and people with disabilities of all types and ages. This part of the statute broadly describes the scope of the state's Medicaid program. It also addresses various elements and operations, including such topics as provider and recipient fraud, estate recovery, transfer of assets, and others. The statute does not specify or enumerate the services that North Carolina's Medicaid program offers nor does it specify the groups of individuals for whom Medicaid services will be provided. Instead, it contains a broad provision that: "The Department may authorize, within appropriations made for this purpose, payments of all or part of the cost of medical and other remedial care for any eligible person when it is essential to the health and welfare of such person that such care be provided, and when the total resources of such person are not sufficient to provide the necessary care." This part of the General Statutes does not contain provisions that are either supportive of or inimical to self-direction of Medicaid services.

  We note that there is considerable policy direction concerning Medicaid services that is incorporated in the Budget Act. The current Budget Act contains a provision that might affect the implementation of self-direction. This provision dictates that Medicaid-enrolled providers must purchase a performance bond in the amount of $100,000. Obviously, such a requirement would be onerous for small provider agencies or individual consumer-hired workers to meet. However, the provision permits DHHS to waive or limit this requirement based on dollar billings.

Statutory Issues Relevant to Division of Aging and Adult Services

- §143B 180-181.55 offers ample statutory basis for the Division on Aging and Adult Services to exercise leadership, technical assistance and monitoring re: consumer directed services. Though there are restrictions placed on the conduct of elder services by the federal statute, the Division also has substantial discretion and funding. The Division, therefore, could theoretically have a more direct and powerful effect on consumer directed service development. Although the statute provides an initial platform for self-directed services, it does not make specific reference to consumer choice or self-direction in the provision of individualized services. §143B-181.3 contains a Statement of Principles which includes some general elements that could be built upon as an initial platform for self-direction:

  (1) Older people should be able to live as normal a life as possible.
  (2) Older adults should have a choice of life styles which will allow them to remain contributing members of society for as long as possible.
  (3) Preventive and primary health care are necessary to keep older adults active and contributing members of society.
  (5) Transportation to meet daily needs and to make accessible a broad range of services should be provided so that older persons may realize their full potential.
  (9) Options in housing should be made available.

- § 131D-19 focuses on the rights of individuals in adult care homes and asserts principles of autonomy within the facility: *It is the intent of the General Assembly that every resident's*

civil and religious liberties, including the right to independent personal decisions and knowledge of available choices, shall not be infringed and that the facility shall encourage and assist the resident in the fullest possible exercise of these rights. § 131D-21 details the specific rights.

- **§** 131E contains a Nursing Home Patients' Bill of Rights covering persons living in nursing homes, adult care homes licensed pursuant to G.S. 131E-102, and nursing homes operated by a hospital which is licensed under Article 5 of Chapter 131E. The statute notes the General Assembly's intent to promote the well-being of persons residing in these facilities beginning with establishing their right to make informed decisions, "...every patient's civil and religious liberties, including the right to independent personal decisions and knowledge of available choices, shall not be infringed and that the facility shall encourage and assist the patient in the fullest possible exercise of these rights".

- §131E-117 sets out a number of particular rights. One considered by advocates and self-advocates to be extremely important -- to present grievances and recommend changes in policies and services, personally or through others without fear of reprisal, restraint, interference, coercion, or discrimination -- is available to those residing in facilities. §131E-124 requires the Department to triage complaints for urgency and to investigate within reasonable time frames set out in the statute. To further strengthen these rights the legislature has given the path of legal remedy for enforcement. §131E-123 provides for the right to pursue a Civil action in order to enforce the rights denoted, and allow for others to institute the Civil action on behalf of a person in the facility. These provisions do not address people receiving home supports or those who are interested in directing their own care.

- §143B-181.15 establishes a Long-Term Care Ombudsman Program in North Carolina to assist residents and providers in the resolution of complaints or concerns, to promote community involvement and volunteerism in long-term care facilities, and to educate the public about the long-term care system. Additionally, the Ombudsman Program serves an important function by its duty to report to the legislature on data related to complaints and conditions, to identify significant problems and recommend solutions. While the Ombudsman Program serves to enhance the quality of life and provides a means to monitor the quality of care for users of long-term care, there is not a parallel program for persons living outside of the statute's defined long-term facilities. §143B-181.16 defines such facilities as nursing homes, intermediate care facilities, and adult care homes.

Statutory Issues Relevant to Division of Mental Health, Developmental Disabilities and Substance Abuse Services

- § 122C-2 (Policy section) contains Olmstead-like language affirming the obligation of the state to provide community based services when such services are appropriate, are unopposed by the affected individuals, and can be reasonably accommodated within existing resources. There is no specific reference to consumer-directed services or consumer choice of services within this general policy construct.

- § 122C-2 defines those services that LME's must make available to all eligible individuals and include (1) screening, assessment and referral; (2) emergency services; (service coordination); and (3) consultation, prevention and education. They are not intended to include or define individualized, community based services that would be provided to "target populations" as defined by the Secretary. While these services and supports might include self-directed options, there is no specific reference to any type of community services or supports, nor to consumer direction, consumer choice, person-centered planning, individualized service planning, etc. Thus there is no statutory policy established that would create an impetus for

LMEs or providers to create such services. Nor is there a statutory basis for consumers to expect or demand consumer-directed or individualized community services or supports.

- § 122C-3 (9a) again defines core services, as screening, assessment and triage or prevention, education or consultation. Specific service types to be available on an equitable statewide basis to defined priority target populations are not enumerated in the statute. There is no reference to specific direct services and supports that should be available to consumers. Nor is there a reference to consumer directed services, person centered service planning, etc.
- It is noted that §122C-3(14) defines the term "facility" as "any person at one location whose primary purpose is to provide services for the care, treatment, habilitation, or rehabilitation of the mentally ill, the developmentally disabled, or substance abusers." This definition would seem to encompass individual staff who are directly hired by consumers under a consumer-directed model, and could potentially be confusing in regard to whether individual staff must meet the requirements of facilities or licensable facilities that are further defined in rules. §122C-3(14)(b) defines a licensable facility as one that "provides services for one or more minors or for two or more adults." §122C-22(8) provides for the exemption from licensure for "facilities" that provide "occasional respite" for two or fewer persons. The implications of these provisions for self-directed supports will be addressed in greater detail during the next phase of this project.
- § 122C-3 (7) defines a client advocate, "whose role is to monitor the protection of client rights or advocate on behalf of a specific client in a facility." This definition is outdated and refers to the "client advocates" who are state employees working in state institutions. In the newer sections of the statute, i.e. Article 1, the term "consumer advocate" is used, which has a broader definition. Given that this definition is confusing, project staff may want to address the issue in the review of rules that follows.
- § 122C-10 – 20 MHDDSA provides for a relatively strong consumer advocacy/consumer rights presence and function at the level of the Secretary of Human Services. All of these sections are subject to appropriation, and there has been no appropriation to date. In the future, implementing these sections could provide a more clear focus and stimulus for consumer directed services and a source of state and local advocacy for such services.
- § 143B-216.65 establishes the North Carolina Traumatic Brain Injury Advisory Council to study the needs of persons with brain injury and their families, and to make recommendations to the Governor and DHHS regarding the planning, development, funding, and implementation of a comprehensive service delivery system. This Council too may assist with promoting and implementing self-directed services.
- § 143B-403.1 creates a statewide protection and advocacy program in accordance with the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. §6000) and the Public Law 99-319 as amended, the Protection and Advocacy for the Mentally Ill Act of 1988. In North Carolina this statewide protection and advocacy program is housed in the Governor's Advocacy Council for Persons with Disabilities (GACPD). GACPD investigates complaints made by, or on behalf of, incompetent persons with developmental or mental disabilities who reside in facilities for the developmentally or mentally disabled who have no legal guardian, and to pursue legal, administrative or other remedies to insure the protection of rights of all developmentally, mentally, physically, emotionally and otherwise disabled persons who are receiving treatment, services or habilitation from any State, local or area program. The GACPD may have a role in promoting and implementing the State's move to providing self-directed services.

Statutory Issues Relevant to Division of Vocational Rehabilitation

- The state vocational rehabilitation statute (GS 143-545.1) calls for individuals with disabilities to be "active participants in their own vocational rehabilitation/independent living programs and shall be involved in making meaningful and informed choices about vocational/independent living goals and objectives and related services they receive" but does not speak to the ability to contract for and manage their own supports.
- Although personal assistance services paid for by Vocational Rehabilitation (VR) through its Independent Living Program are more flexible and consumer-directed than personal assistance services paid for by Medicaid, VR can only provide them to a few people per year because of budget constraints. The Independent Living Program is not really funded to expand services to new individuals unless individuals currently on the program stop receiving those services. If a person has another source of payment (e.g. Medicaid/Medicare), it is always billed first. Due to limited funding, the number of persons accessing VR personal assistance remains small. The VR personal assistance program that is connected to vocational training and employment is time-limited.
- The Client Assistant Program (CAP) was established as a mandatory program by the 1984 Amendments to the Rehabilitation (Rehab) Act of 1973. The Client Assistance Program helps people with disabilities to gain access to needed rehabilitation and other supports. Helping people make informed decisions with choice and realize their choices is a tenet of self-direction. CAP services include assistance in pursuing administrative, legal and other appropriate remedies to ensure the protection of persons receiving or seeking services under the Rehabilitation Act of 1973. In North Carolina CAP serves applicants, clients, former clients, and those seeking the services of the Division of Vocational Rehabilitation Services, Division of Services for the Blind, and the Independent Living Rehabilitation Services. North Carolina's Vocational Rehabilitation Services statute §143-545.1 through 548 require the state adopt rules as required by the Rehabilitation Act of 1973, thus our review of constraints to self-determination will continue to the next phase of review.

Statutory Issues Relevant to Division of Services for the Deaf and Hard of Hearing & Division of Services for the Blind

- There were no major constraints to self determination in statute governing services to either Division beyond issues noted above in the general statutory issues section.
- § 143B-163 establishes a Consumer and Advocacy Advisory Committee for the Blind responsible for continual study of the entire range of problems and needs of the blind and visually impaired population of North Carolina and to make specific recommendations to the Secretary of Health and Human Services as to how these may be solved or alleviated through legislative action. As the Committee is to examine national trends and programs of other states, as well as programs and priorities in North Carolina, committee members will play an important role in the development of self-directed services for this population.
- § 143B-216.31 establishes the Council for the Deaf and Hard of Hearing to, among other charges, make recommendations to DHHS on improvement to services and to advise on the quality of services. This Council also could play a role in advancing self-direction for persons with deafness and those who are hard of hearing.

Statutory Issues Relevant to Division of Social Services

- There were no significant constraints to self determination in statutes governing services to and protections for children.

Statutory Issues Relevant to Home Care Services

- "Home care services" are defined in Chapter §131E-136(3) as including nursing care as well as "in-home aide services that involve hands-on care to an individual." The statute specifically excludes from the definition of "home care services" (and, hence, licensing): (a) programs operated under the authority of §122C and (b) as noted above, services rendered by "an individual who engages solely in providing his own services to other individuals." The exclusion of individual providers of home care services from licensure likely will facilitate self-direction. The provisions of this statute and its associated regulations will prove to be especially important in the context of promoting self-directed supports for persons with disabilities and elders.
- §131E-256 provides for the establishment of a Health Care Personnel Registry to compile information about workers who have committed abuse and neglect. Workers included in the scope of this registry include employees of adult care homes, home care agencies, and residential agencies (but not services provided outside residential or 24-hour agencies) under 122C. Here again, this statute applies to traditional provider agencies but does not appear to apply to individuals who might be directly employed by a service recipient.

Cross-Population Statutory Issues

- Chapter §97 (Workers' Compensation Act). A major concern in implementing self-direction is that service recipients might be liable when the workers whom they hire are injured on the job. When services are obtained through traditional providers, those providers address this type of liability by purchasing workers compensation insurance. However, acquiring such insurance can be difficult for service recipients. North Carolina's present workers' compensation laws do not appear to be especially well-geared to supporting self-direction. Workers' compensation insurance is only mandatory when an employer employees ten or more "domestic service workers" (the most common classification for personal assistants who provide support in a self-directed model). While it is theoretically possible for individuals to voluntarily purchase workers' compensation insurance for personal assistants, it is reported that such insurance is "non-existent" in North Carolina. North Carolina's Workers' Compensation Act may need to be modified to accommodate self-direction. Going forward, DHHS and the state's Industrial Commission should collaborate to identify potential changes in North Carolina's laws or policies to accommodate self-direction.[†]

[†] For information concerning this complicated topic (including accommodations that other states have made, please see: Susan A. Flanagan, M.P.H. (2004). **Accessing Workers' Compensation Insurance for Consumer-Employed Personal Assistance Service Workers: Issues, Challenges and Promising Practices**. Washington DC: The Westchester Consulting Group. Available at: http://www.hcbs.org/files/43/2104/060704_WC_Final_Report_Narrative_-Final_Version.pdf.

RECOMMENDATIONS

- The general provisions for the Department of Health and Human Services (DHHS) should be amended to include specific intent language regarding and encouraging the development of self-directed supports across all of the populations served by DHHS. The language should include the values and principles associated with self-direction and note the potential of self-direction in an operational framework (e.g., person centered planning, individual budgets, etc.). Proposed language is included in Attachment A.
- The North Carolina Workers' Compensation Act may need to be modified to accommodate self-direction. Going forward, DHHS and the state's Industrial Commission should collaborate to identify potential changes in North Carolina's laws or policies to accommodate self-direction.
- As self-direction takes hold in North Carolina, the Legislature should develop uniform state requirements for criminal background checks that encompass the individuals hired through any current or future self-directed initiative. The present requirements revolve around the employment of individuals by traditional provider agencies. They do not speak directly to the employment of workers by service recipients.
- §143-15.3D (Trust Fund for Mental Health, Developmental Disabilities, and Substance Abuse Services and Bridge Funding Needs) is to be used for start-up funds for services that provide more appropriate and cost effective community treatment alternatives; facilitate compliance with the Olmstead decision; and facilitate reform of the MHDDSAS system. Use of some portion of the funds (if there are any left) to fund pilot programs of consumer-directed services in the MHDDSAS system would seem to be clearly within the scope of this section.
- The issues surrounding State and County Special Assistance, the differential "spend down" requirements for Medicaid eligibility (e.g., living in your own home versus living in an Adult Care Home), as well as the "100% of poverty" eligibility standard should be assessed in the impending institutional bias study.
- The General Assembly Legislative Study Commission established pursuant to Session Law 2004-161 should ensure that its review takes into consideration the relationship of current guardianship provisions to the exercise of self-direction on the part of individuals who are aging, and who have physical and developmental disabilities. Specifically, the Commission should ensure that other options to support decision-making such as advance directives, designation of health care proxies or powers of attorney, use of independent support or brokerage, fiscal intermediaries, and other similar planning tools are used prior to considering guardianship for individuals who are self-directing their services. Where guardianship is necessary, the state should strongly support the use of limited guardianship.
- As noted above, client protections within a self-directed system pose challenges to conventional quality assurance approaches. In light of the expected expansion of self-direction and the concomitant pressure to develop less traditional supports and more individualized settings, the fit between conventional licensing and "facility definitions" will become more and more strained. The current statutes that define "facility" – licensable and otherwise – did not anticipate self-direction nor did the current licensing rules. To address the mismatch between more conventional concepts of "facilities" and "programs," the Department should establish an interagency task force to review licensing reforms, to explore the separation of "facility" concerns from program concerns, and statutory/regulation changes. Project staff will address potential rules changes in the next phase of this project.

Attachment A
Proposed Amendments to Section 143B of the North Carolina Statutes

Note: The Department of Health and Human Services is established by § 143B. 136-216. Within this statute, the following proposed amendments would occur in two places. One amendment would insert language into the Department's enabling statute; the other would insert language to enable the Secretary to execute rulemaking.

Current language
"§ 143B-137.1. Department of Health and Human Services – duties.

> *It shall be the duty of the Department to provide the necessary management, development of policy, and establishment and enforcement of standards for the provisions of services in the fields of public and mental health and rehabilitation with the intent to assist all citizens – as individuals, families, and communities – to achieve and maintain an adequate level of health, social and economic well-being, and dignity. Whenever possible, the Department shall emphasize preventive measures to avoid or to reduce the need for costly emergency treatments that often result from lack of forethought. The Department shall establish priorities to eliminate those excessive expenses incurred by the State for lack of adequate funding or careful planning of preventive measures. (1997-443, s. 11A.3.)"*

§ 143B-137.2. Proposed amendment establishing and promoting Consumer Self-Directed Services

> The State of North Carolina affirms the authority and responsibility of citizens to exercise control over their lives, including the manner in which services and supports are furnished to them. Self-direction of services and supports by people with disabilities or elders is recognized as a way for these citizens to exercise choice and control and is supported as one option under a continuum of services offered under the Department. Self-direction at a minimum includes personal control of the type of services to be received, the manner in which the services are delivered, and the selection and oversight of the person(s) providing the services and supports.

The proposed amendment to provide for Secretary rule-making would be inserted as follows:

§ 143B-139.1A. Secretary of Health and Human Services to adopt rules applicable to Consumer Self-Directed Supports

> The Secretary of the Department of Health and Human Services may develop, implement and expand voluntary options for individuals to self-direct services across the full range of programs under the management of the department. In furtherance of this objective the Secretary may adopt and enforce rules; may implement new service financing mechanisms; may amend or waive department rules and regulations under the Secretary's authority; and may establish standards, quality measures and performance benchmarks related to the implementation and expansion of self-directed service throughout the department.